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Camp gives ailing kids week of fun

By C.W. Nevius

One child in 20,000 is born with the skin disease epidermolysis bullosa. Lana Coil has three of them.

The disease, known as EB, leaves the skin extremely fragile and impairs its ability to bond to the body. Even the slightest amount of friction can cause painful sores and blisters, or make the skin literally slough off. Those who have EB lead incredibly sheltered lives - even something as simple as a bath may require a dose of morphine — and don't usually live much beyond their 20s. Coil recalls attending the funeral of an EB-afflicted friend who, she says, "lived a long, long life." He was 38.

For a kid with EB, a "normal" life is next to impossible. That's why two of Coil's three children — 11-year-old Alex and 10-year-old Brandi — are looking forward to next week's Camp Wonder in Livermore. For one week, they'll be able to run around with other kids like them, laughing and playing and perhaps even going for a swim.

Camp founder, Francesca Tenconi, a 21-year-old who lives in Walnut Creek and who has a skin disease herself, funds the camp through her nonprofit Children with Skin Disease Foundation (www.csdf.org). She says the week can be transforming.

"A lot of the kids have been teased at school or made to feel unwelcome in public. We try to foster a positive environment," Tenconi says. "One mom last year said her son 'shed his disease.' In a way, that happens to all of them."

But the camp also provides a break to those who care for children with EB.

Someone like Coil.

Coil led a fulfilling, but very different, life five years ago. She was a lawyer, "staying up until 4 in the morning working on cases and loving it. She defended the underdogs, taking on cases involving AIDS and HIV, age discrimination and disability claims.

In 2000, after closing a case at her office in Oakland, she visited her mother and father, Lee and Sheryl, in Napa. Lana sometimes thought her parents, although wonderful people, were "crazy" for opening their home to six foster children with severe disabilities. Three of them — Corey, Alex, and Brandi — had EB.

The kids came to Lee and Sheryl after Corey and Alex were taken from their parents, who were sometimes homeless and often lost in substance abuse. Doctors warned them after Corey's birth that any subsequent children probably also would have the disease. Nevertheless, Alex came along the next year, followed by Brandi 12 months later.

All were born with EB, although the genetic disease grew less severe with each child. To Coil, caring for such a desperate group seemed incomprehensible. But that task fell to her when her mother unexpectedly collapsed and died that week-end five years ago.

Coil knew what she had to do. She resigned from the law firm two days later to care for Corey, Alex, and Brandi.

"People said, 'Are you crazy?'" she says. "To me it was a no-brainer."

Coil told the kids she wouldn't be their mother when she took on the job, just their sister, but relented in 2002 and adopted them.

"It was," she says, "time for an upgrade."

They live in Grass Valley (Nevada County) and have settled into a routine of bandages, all manner of pills and ointments and regular trips to Lucile Packard Children's Hospital at Stanford, one of the few clinics in the United States that specializes in EB.

"There's nothing left of my previous life," Coil says. " 'Rolle Polie Olie' (a kid's TV cartoon) —



Corey Coil receiving a Gift.



Alex Coil, waiting for his turn to answer question, during Camp Wonder "Dating

that's my life now."

The kids have their niches. Alex is a movie buff with a taste for horror flicks. He managed to watch "Halloween" the other night because, he grins, "Mom fell asleep." He climbs out of his electric wheelchair for brief walks, although he is swaddled in bandages, and loves to draw. One of EB's symptoms is that the fingers and toes begin to web together, but that doesn't bother him much.

"I don't care about these fingers," Alex says, holding up his pinkie and ring finger. But he uses his thumb, index and middle fingers to hold a pencil, and so "I care about those three."

Brandi is so outgoing and confident that she will start conversations with strangers, and she has such an interest in wildlife that it is not unusual for her to stroll into the house carrying a praying mantis. She walks well, although a little stiffly, and hardly shows any of the telltale open sores and blisters common with EB.

"She's such a wonderful kid," Lana says. "So close to being normal. I have such high hopes for her."

Brandi stands in stark contrast to Corey, who is 12. A botched surgery left him with bandaged stumps at the end of his arms. There are days when the pain is unbearable. It isn't just that his skin is so fragile that something as soft as a shirt collar can cause sores. His body simply will not heal. Wounds suffered as an infant remain raw even now. He knows he is slowly dying, and he's at peace with that.

"Corey wants to die. Sometimes he begs," Coil says. He doesn't want doctors to resuscitate him when he goes, and told her, "If I am on my way to heaven, don't turn me around."

"Corey says he can't wait to get to heaven," Coil says. "He just wants to be able to run."

Corey will never run. But for a week, at Camp Wonder, his brother and sister can run for him.

C.W. Nevius' columns appear Tuesday and Saturdays in the Bay Area section and on Fridays in East Bay Life. E-mail him at cwnevius@sfchronicle.com

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